

Medicaid Managed Long Term Services and Supports for People with Intellectual and Developmental Disabilities

Kansas Department of Aging and Disability Services

Part 1 of 2

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National Association of State Directors of
Developmental Disabilities Services**

NASDDDS

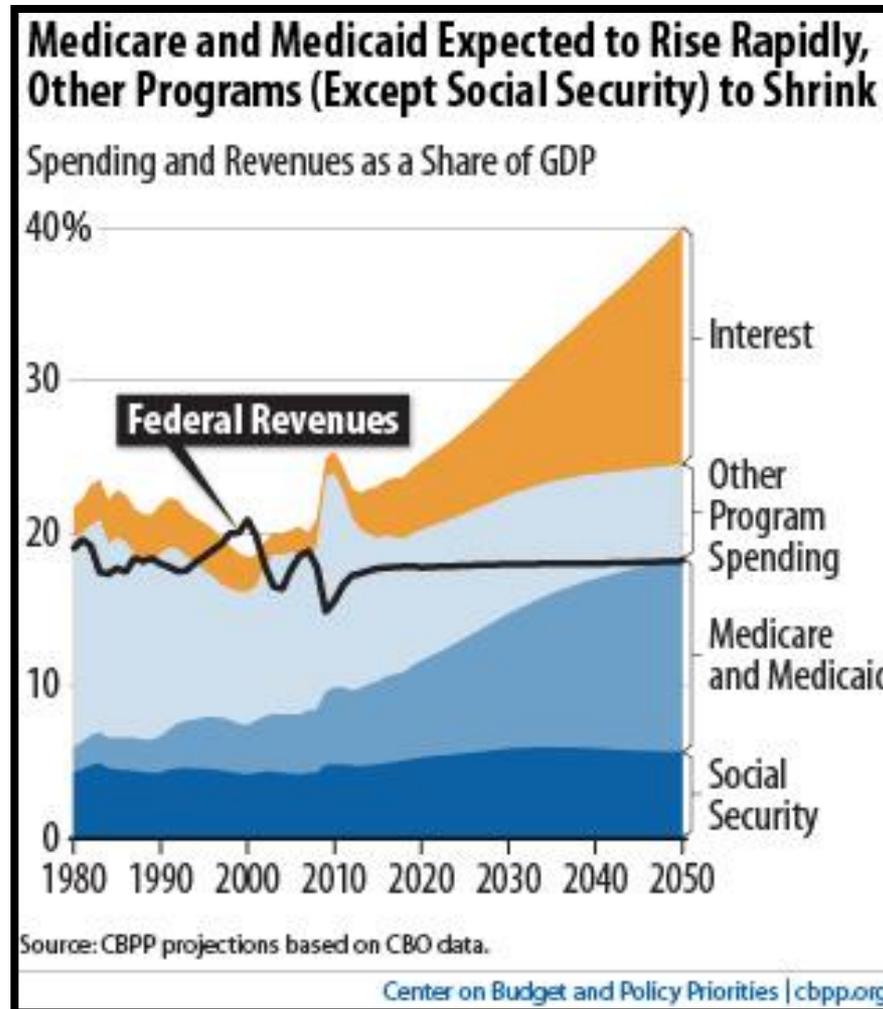
Sept. 18, 2013



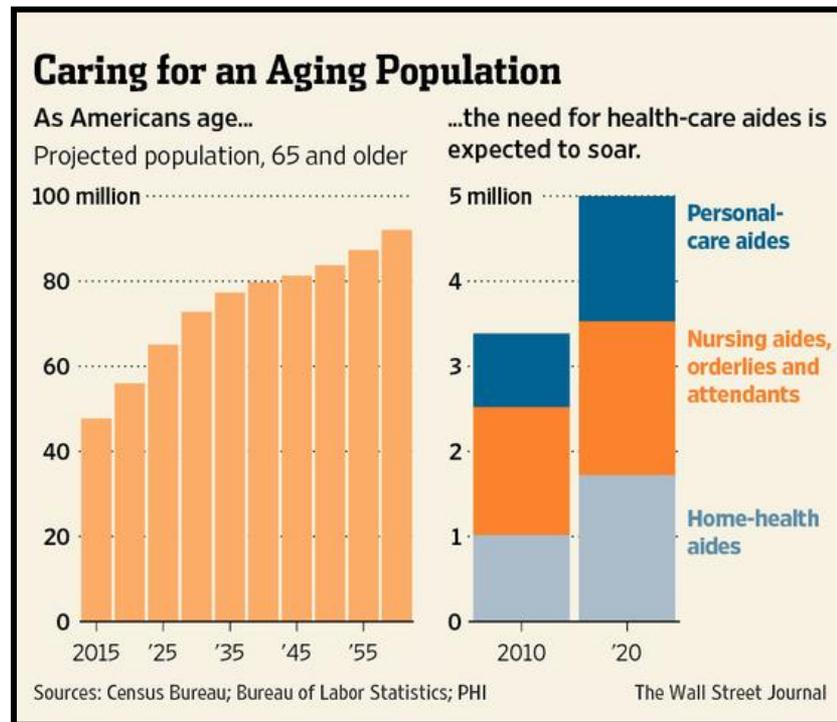
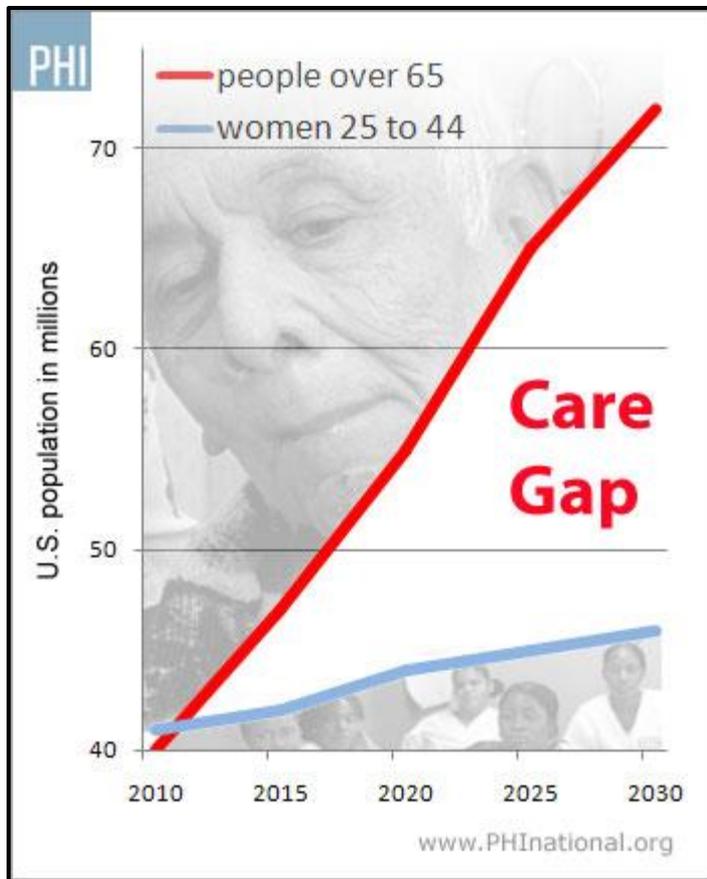
NASDDDS

National Association of State Directors of Developmental Disabilities Services

Medicare and Medicaid



The Care Gap



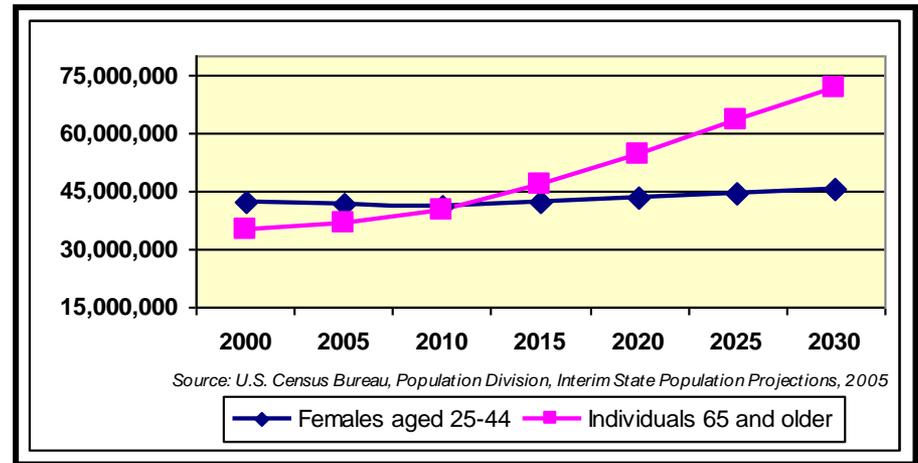
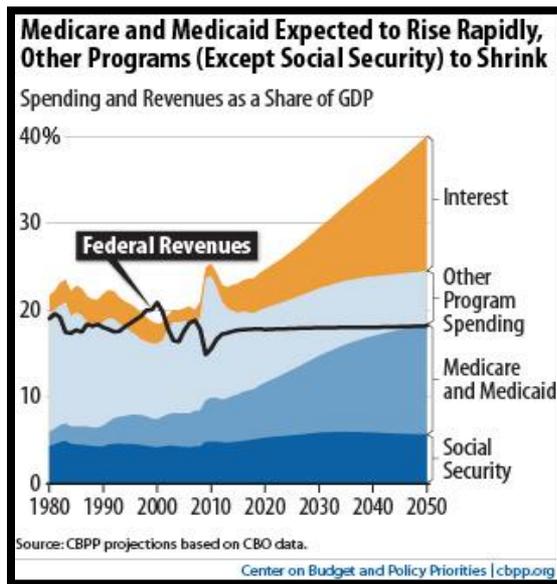
A labor shortage is worsening in one of the nation's fastest-growing occupations—taking care of the elderly and disabled—just as baby boomers head into old age.

Wall Street Journal April 15, 2013

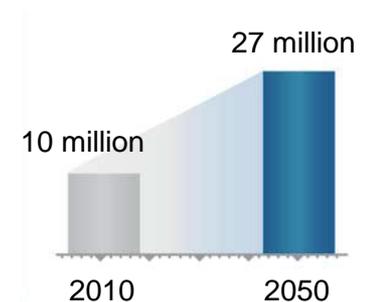
We are Confronted with Reality

Workforce will not keep pace with demand

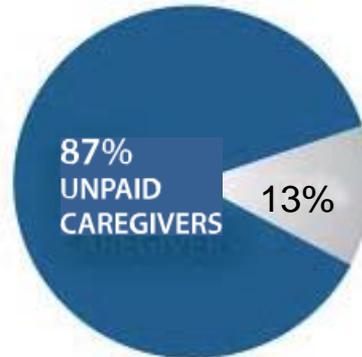
Growth in public funding will slow



The Demand for Long Term Supports is Growing



87% of the 12 Million Americans Who Need Long-Term Care Receive It From Unpaid Family Caregivers*

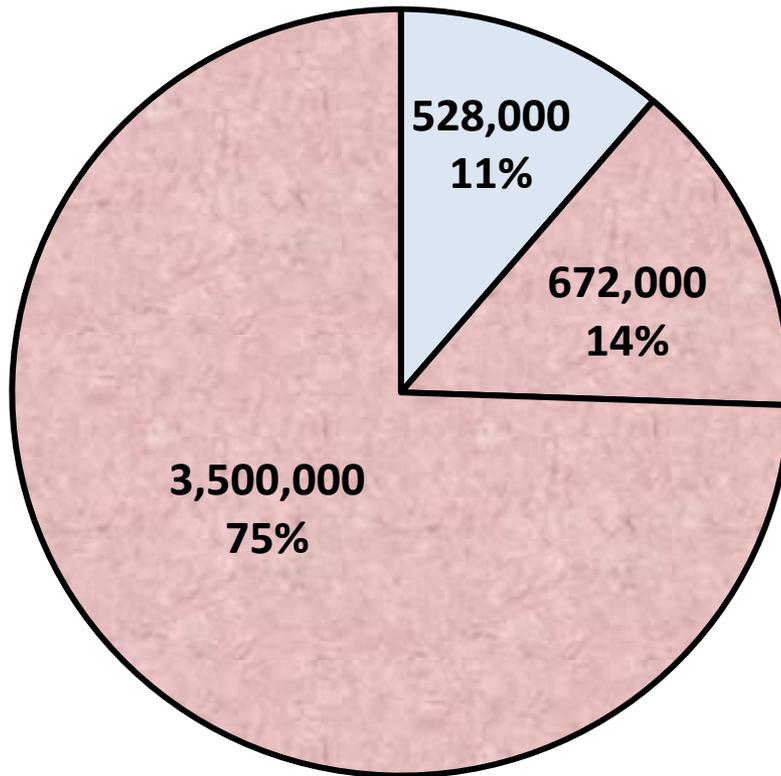


20%–30% physicians, nurses, and therapists

70%–80% home health aides, certified nursing assistants, and personal care aides

* Estimated annual value of unpaid care in 2009: \$450 billion

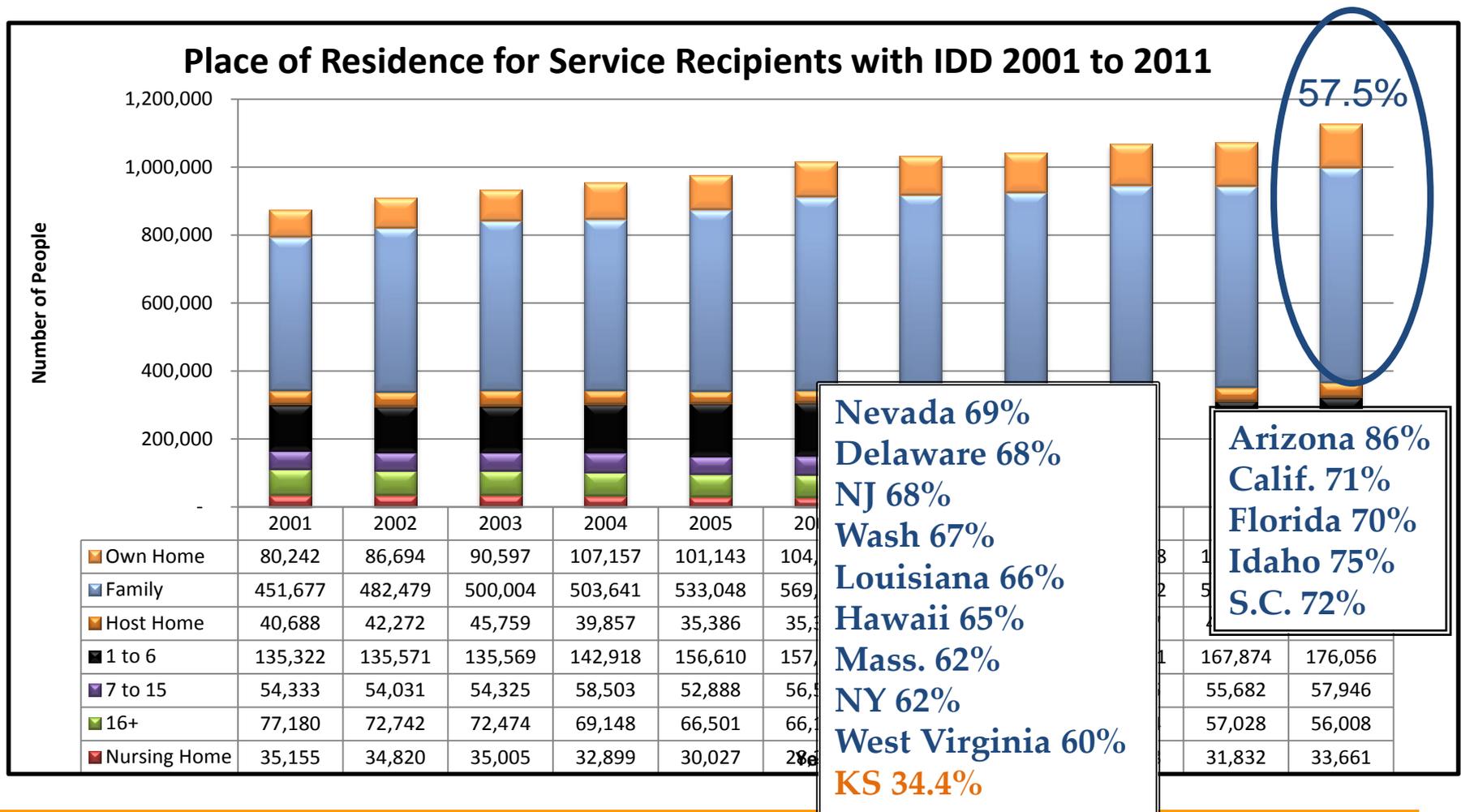
People Living with Family - 89%



4.7 Million people with I/DD

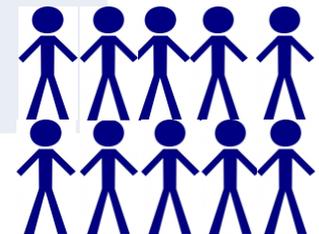
- Receiving Services Out of Home
- Receiving Services Living at Home 14%
- Not Receiving Services - Living at Home 75%

Most People with IDD in Service Live with Family



Cost of Long Term Supports - IDD

Type of Service	Cost per Person	20 yrs. Cost	30 yrs. Cost
Institution	\$238,500	\$4,770,000	\$7,155,000
HCBS 24 hr. staffed Residential	\$150,000	\$3,000,000	\$4,500,000
Shared Living Host Home Adult Foster Care	\$50,000	\$1,000,000	\$1,500,000
Support in Own or Family Home	\$25,000	\$500,000	\$750,000



Data Source: Lakin, K.C. MSIS and NCI data from 4 states (1,240 Individuals)

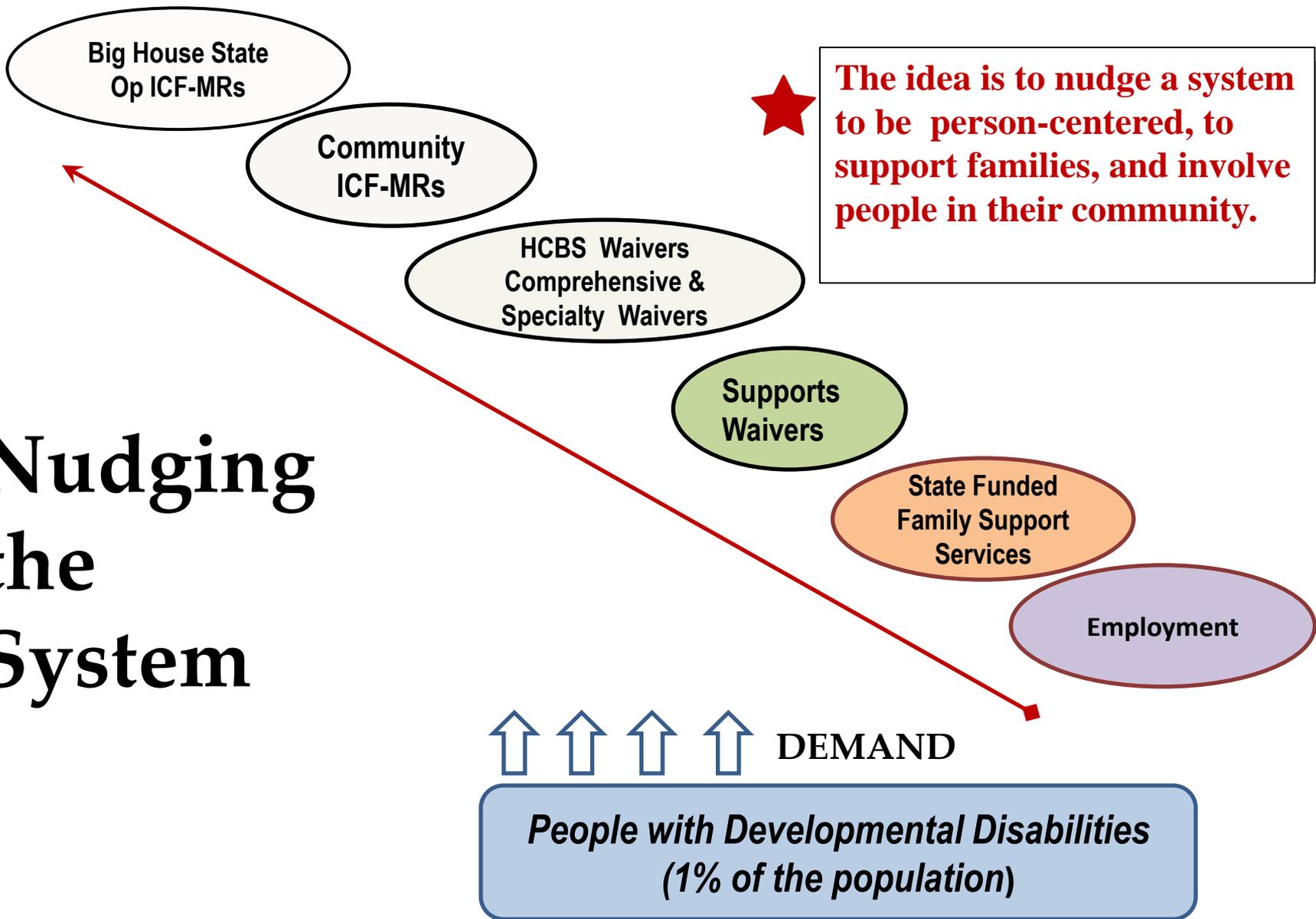
The Question Is.....

Not whether people who need long term supports and services will be living with and relying on their families for support but.....

whether people and their families will struggle alone or have a great life because the supports are there for them and they are part of their community.

Service Models

Nudging the System



Why Focus on Employment?

- ✓ **Get out of poverty**
- ✓ **More independence**
- ✓ **Make Friends**
- ✓ **Make a contribution to the community**
- ✓ **Positive image and valued role within the family and community**
- ✓ **Opportunities for learning and expanding relationships**

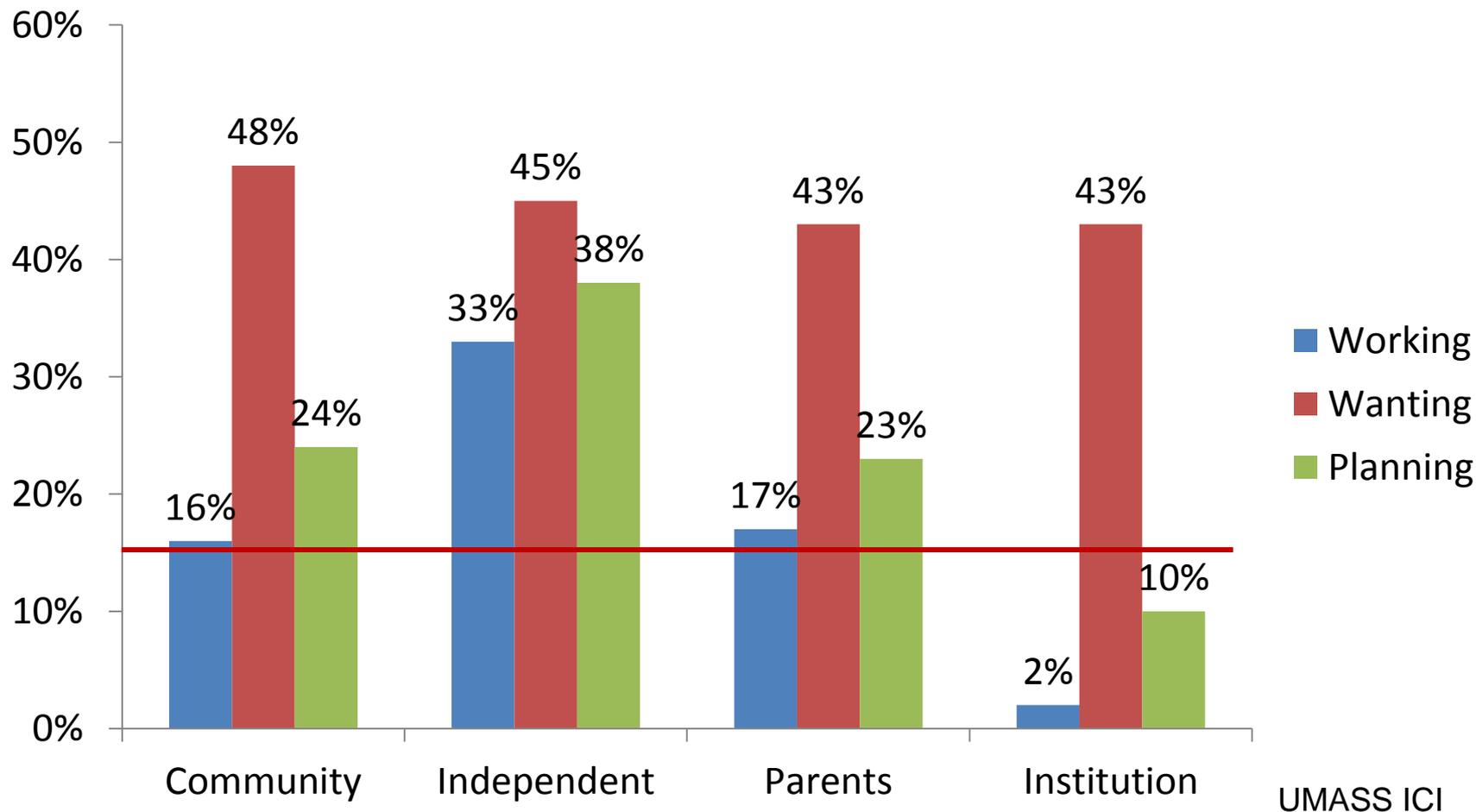


Think for the Long Term About Cost - Employment

Type of Service	1 yr. Cost	3 yr. Cost	10 yr. Cost
Sheltered Work/Day Habilitation	\$20,000	\$60,000	\$200,000
Employment Services	\$20,000	\$50,000 <ul style="list-style-type: none">• \$20,000 yr. 1• \$20,000 yr. 2• \$10,000 yr. 3	\$120,000 <ul style="list-style-type: none">• \$50,000 - 3 yrs.• \$70,000 - 7 yrs. (\$10,000 per yr.)

Estimated figures – use your own figures and do the math

Plans Don't match people's desire to work



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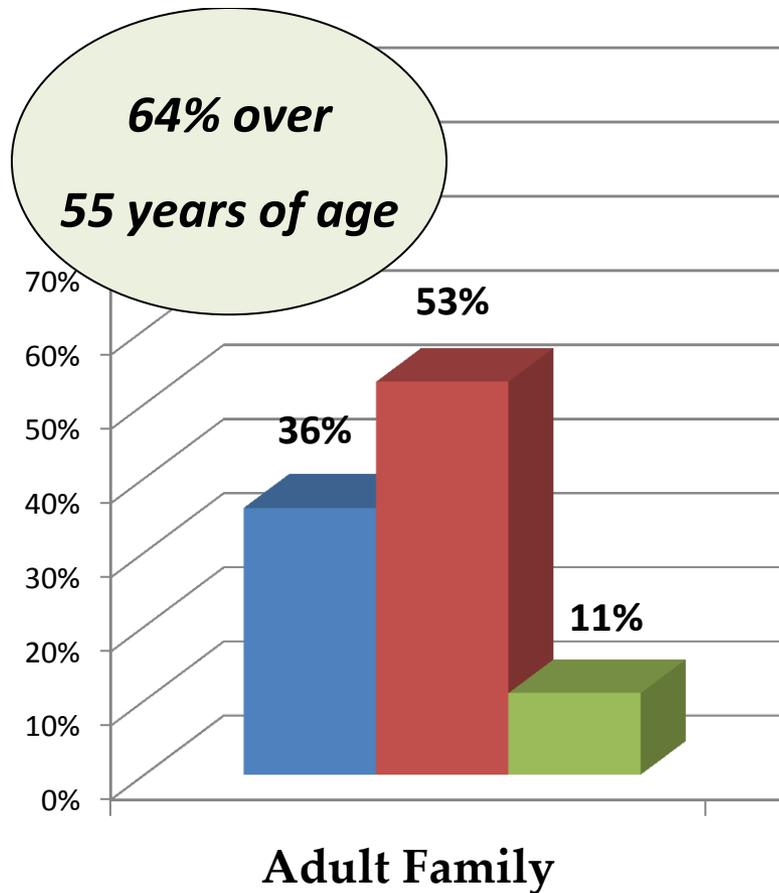
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Creating a New Service Paradigm for Families

**Sustainability
depends on how well we
support families and get
people jobs.**



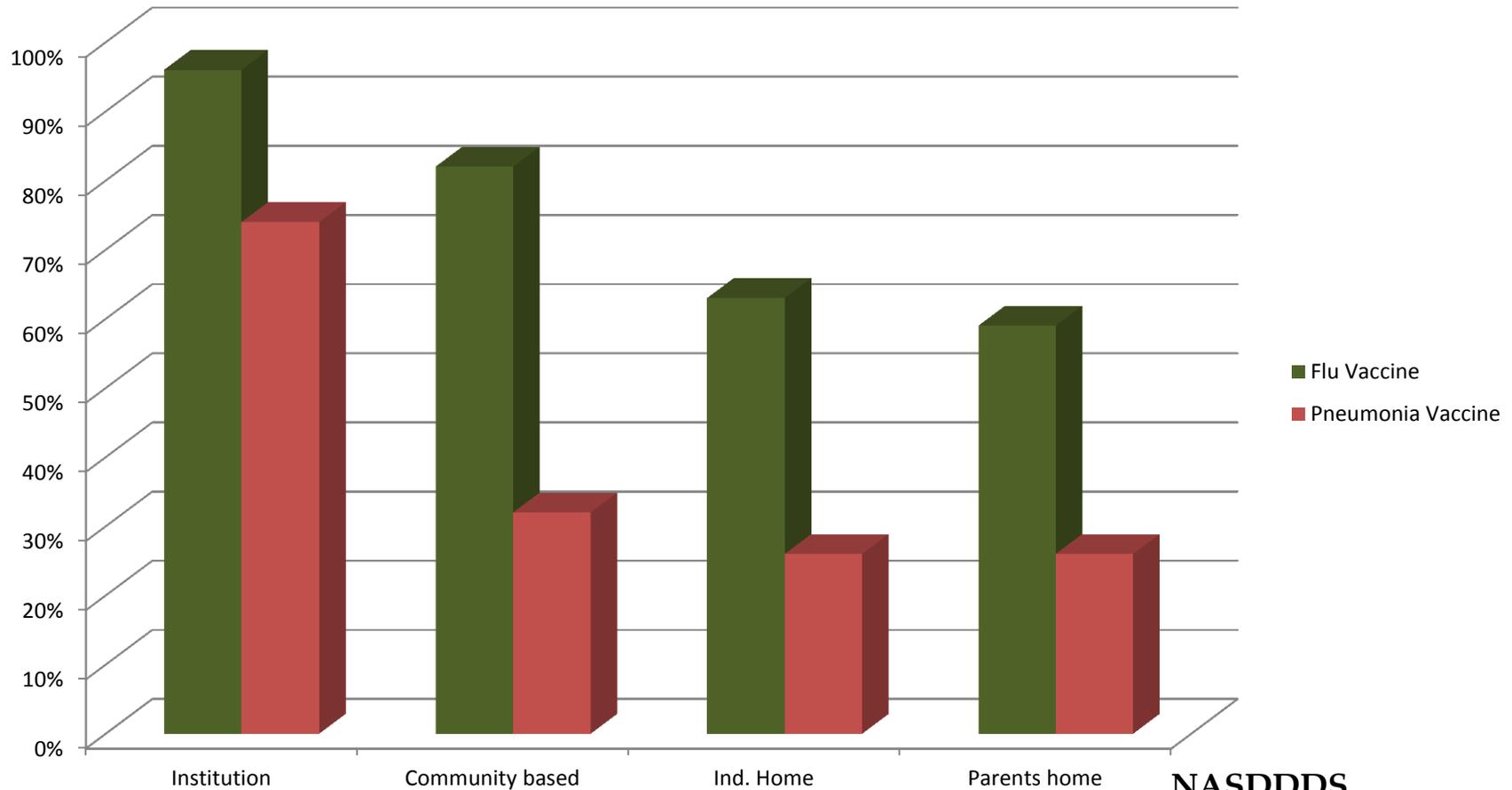
Many Caregivers are over 55



NASDDDS
National Core Indicators

People living at home

Access to Care



NASDDDS
National Core Indicators

NASDDDS

National Association of State Directors of Developmental Disabilities Services

Families are Not Group Homes

- Families include parents; siblings; grandparents; other relatives
- Families are complicated. Family
 - Help each other; they sacrifice for one other;
 - Hurt each other; they apologize and forgive;
 - Have fun and celebrate with each other
 - Have routines, customs and habits – they have their way of doing things
 - Have secrets and things they don't talk about
 - Have troubles, get tired and discouraged
 - Do the impossible
 - Commit abuse and take advantage of other families members
 - Can't do everything
 - Etc. etc. etc.
- The family is the context for everything; personal outcomes will be influenced by the family



Families are in it for the Long Haul - The Life Course



Domains of Supports to Families

DISCOVERY AND NAVIGATION
Information and Training Supports

PEER SUPPORT NETWORKS
Emotional Supports

DAY-TO-DAY NEEDS
Supports for Role of Daily Care/Support

Supporting Individuals and Families Across the Life course

Discovery and Navigation *Information and Training Supports*

- Information on disability
- Knowledge about best practices and values
- Skills to navigate and access services
- Ability to advocate for services and policy change

Peer Support Networks *Emotional Support*

Day to Day Needs *Supports for Role of Daily Care/Support*

Supporting Individuals and Families Across the Life Course

**Information and
Training
Supports:**
*Knowledge
and Skills*

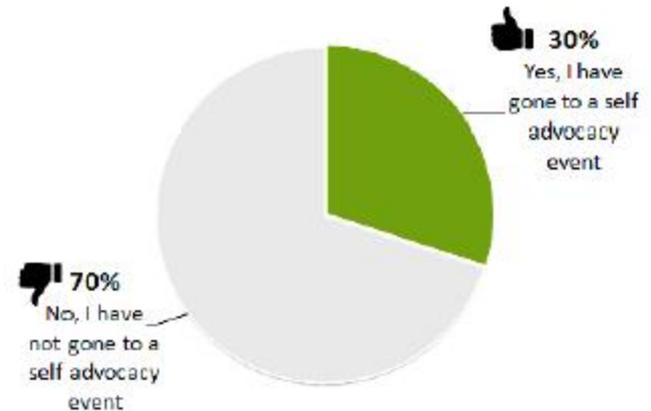
PEER SUPPORT NETWORKS
Emotional Supports

- Parent-to-Parent Support
- Self-Advocacy Organizations
- Family Organizations
- Sib-shops
- Support Groups
- Professional Counseling
- Non-disability community support

**DAY-TO-DAY
NEEDS**
*Supports for Role of Daily
Care/Support*

Self-advocates Networking

Have you gone to a self-advocacy meeting?



NCI tells us **3** out of every **10** people say they **have gone to a self-advocacy meeting.**

Supporting Individuals and Families Across the Life Course

**Information and
Training
Supports:**
Knowledge and Skills

**PEER SUPPORT
NETWORKS**
Emotional Supports

DAY-TO-DAY NEEDS

Supports for Role of Daily Care/Support

- Self/Family-Directed services
- Transportation
- Respite/Childcare
- Adaptive equipment
- Home modifications
- Financial assistance
- Cash Subsidies
- Short/Long term planning
- Caregiver Supports and training

Ethical Issue: Training and Support for the Supporters

It is crucial to provide **ongoing supervision from a clinician with expertise in family dynamics** to identify issues as they emerge, to help staff be aware of their feelings and reactions, and to review ethical standards, and to act accordingly.

- **A staff member in the family home on a daily basis begins to be seen as one of the family. Family professional boundaries can be easily crossed, as families share more and more and as the staff member sees the family in every aspect of home life. Families may begin to**
 - **ask for additional help, like child care,**
 - **suggest social contacts,**
 - **invite staff members to family events, birthday parties**
 - **give gifts to staff, and staff may want to give gifts to family members.**

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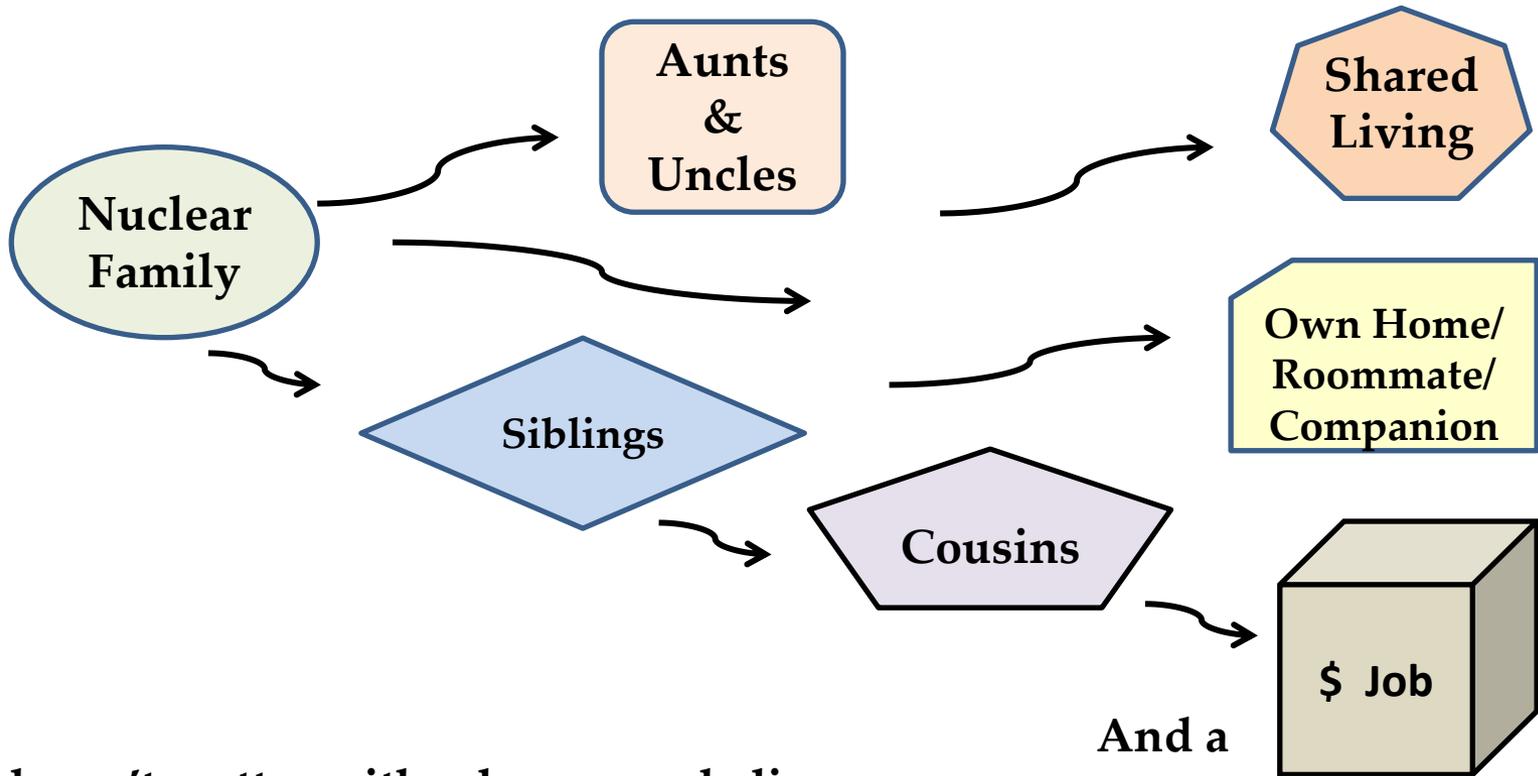
- Staff members may become emotionally involved in family members' lives
 - pulled into marital disputes, and
 - privy to private conversations.
- Staff members may develop strong feelings about the family's
 - ways of parenting,
 - interacting,
 - housekeeping,
 - daily habits,
 - financial practices,and these feelings may affect the staff members' interactions with the family, making it harder to maintain their role.

Does Everyone Have to Live with Their Family?

No. It means we have to maximize the extent to which as many people as possible can live great lives without 24 hours of paid supports using **RELATIONSHIP BASED OPTIONS**

- Family
- Extended Family
- Friends
- Shared Living
- Independently or with a friend
- Paid Companion

Relationship Based Living Arrangements



**It doesn't matter with whom people live,
the supports should match what they need so that.....**

Top Service Challenges for States

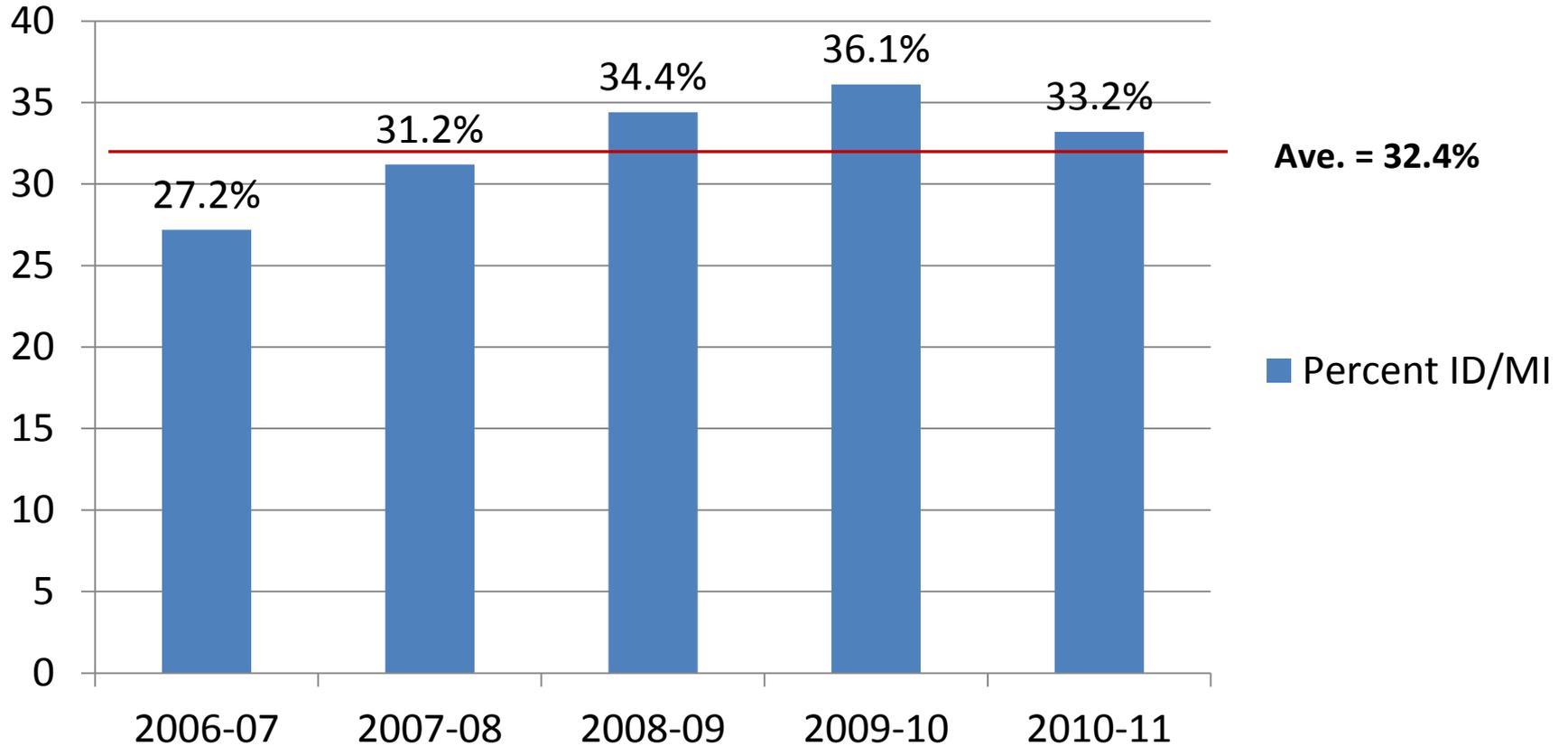
- People with challenging behavior – highest cost individuals
 - Criminal offenses adjudicated and non-adjudicated
 - Sexual offenders
 - Mental health disorders
- Waiting Lists
- Managing Cost – equity, fairness and reasonableness
- Implementing promising practices – person centered practices; positive behavioral approaches; employment; Autism
- People with significant medical care needs

Causes of Challenging Behavior

- Undiagnosed or untreated mood disorder
- Undiagnosed or untreated post traumatic stress
 - Sexual abuse >75%
 - Exclusion, rejection, bullying and humiliation 100%
 - Frustration from awareness of limitations
- Undiagnosed or untreated depression
 - Biological
 - Environmental/social – loneliness
- No knowledge of neurological challenges i.e. Autism, Fragile X etc.
- Support models and practices that are not person-centered
- No awareness of treatment options
 - DBT
 - EMDR

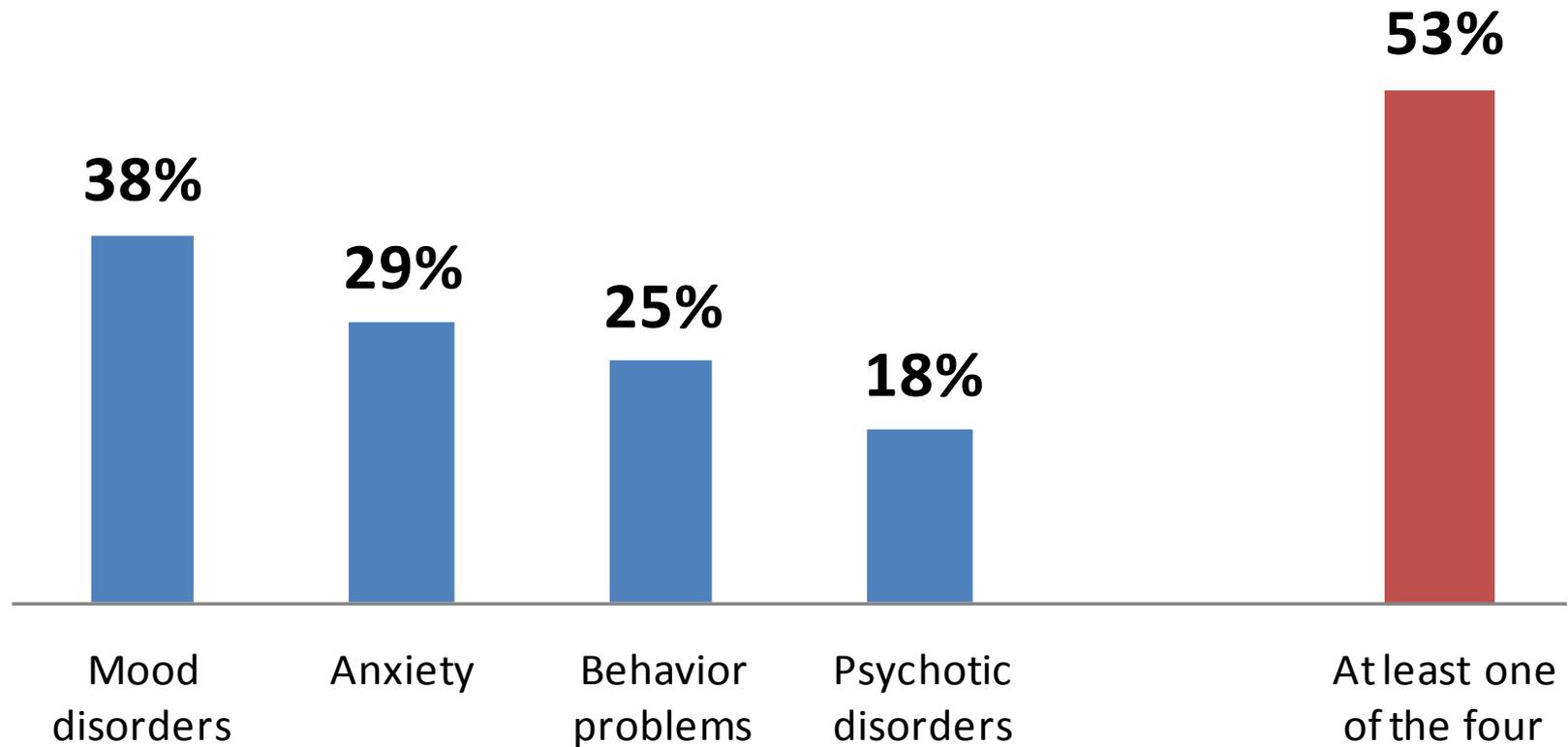
Prevalence of IDD/MI:

Percent ID/MI

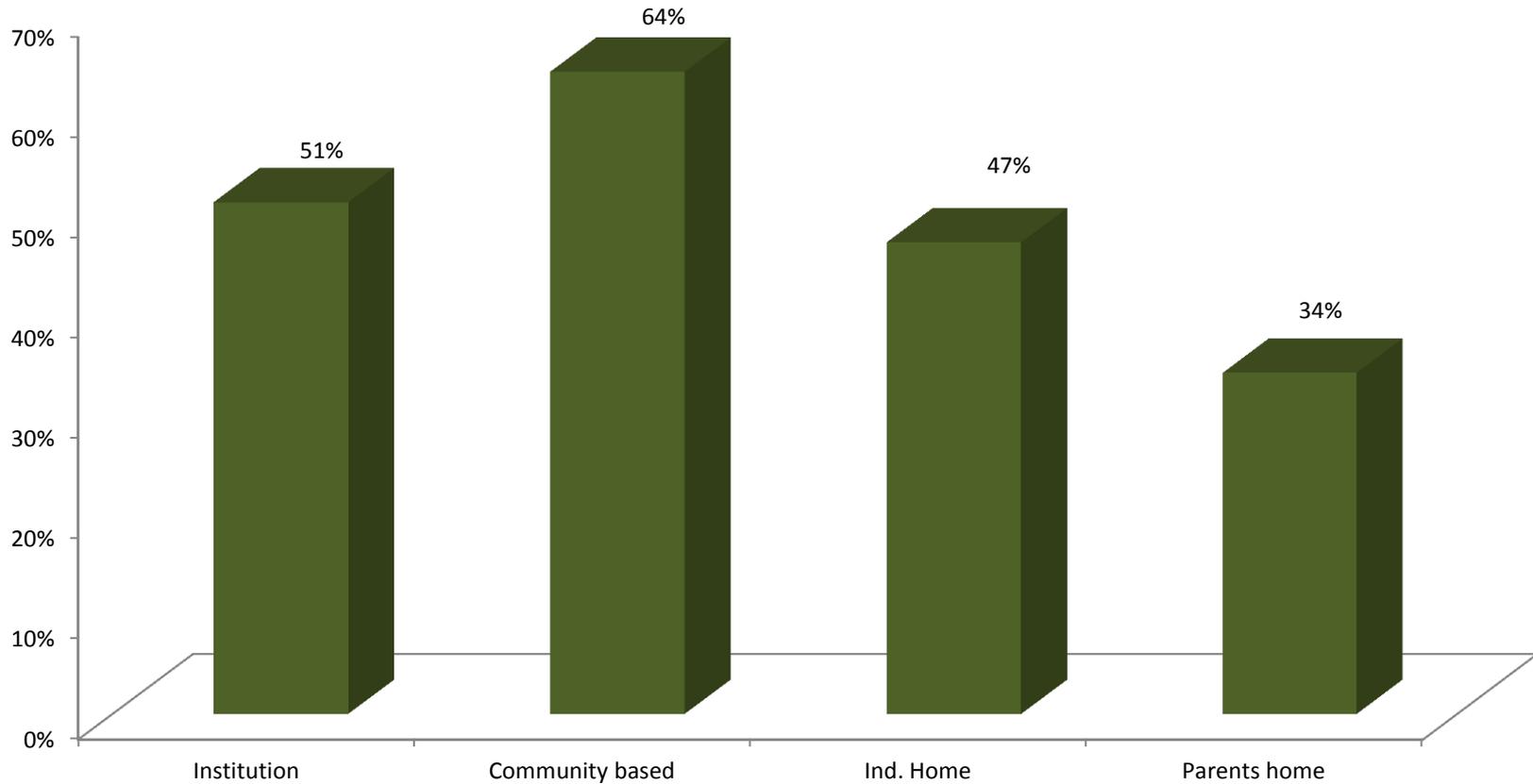


www.nationalcoreindicators.org

Takes medications for.....

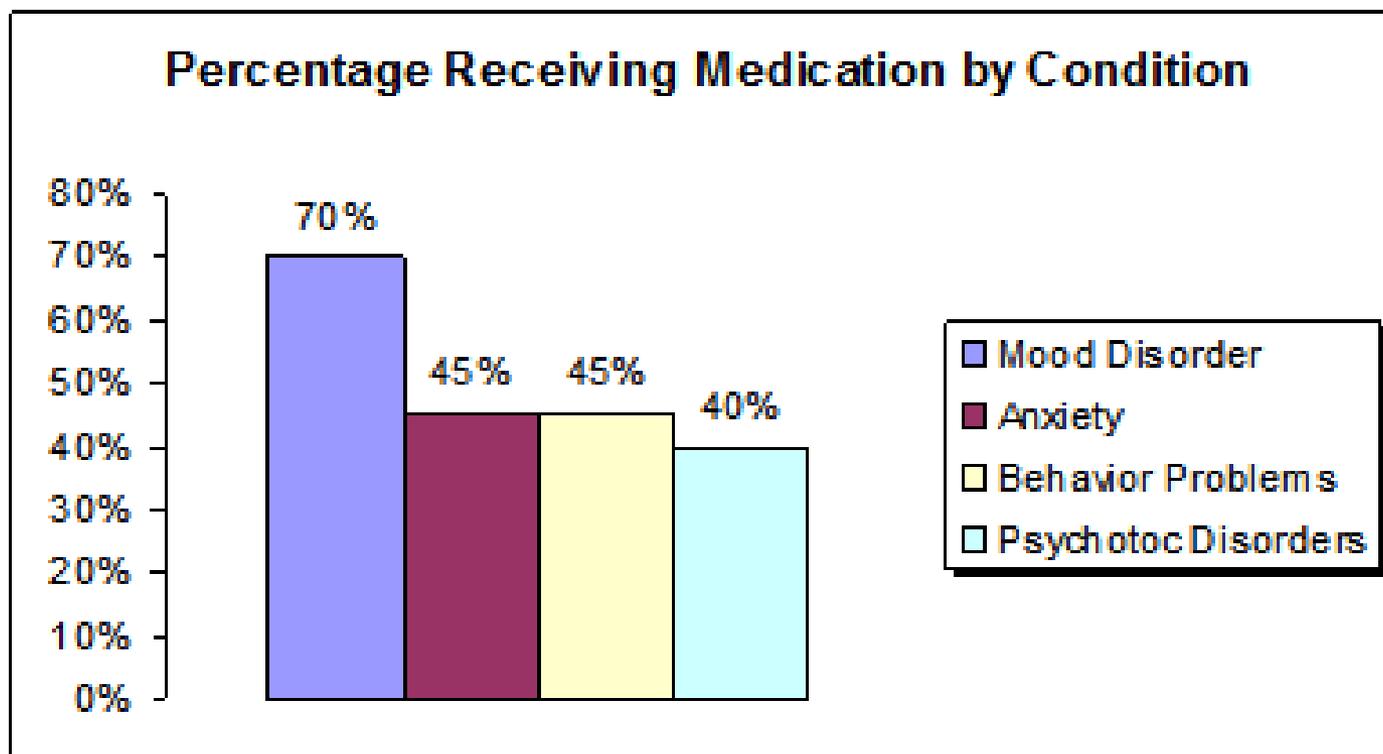


At Least One Psychotropic Medication



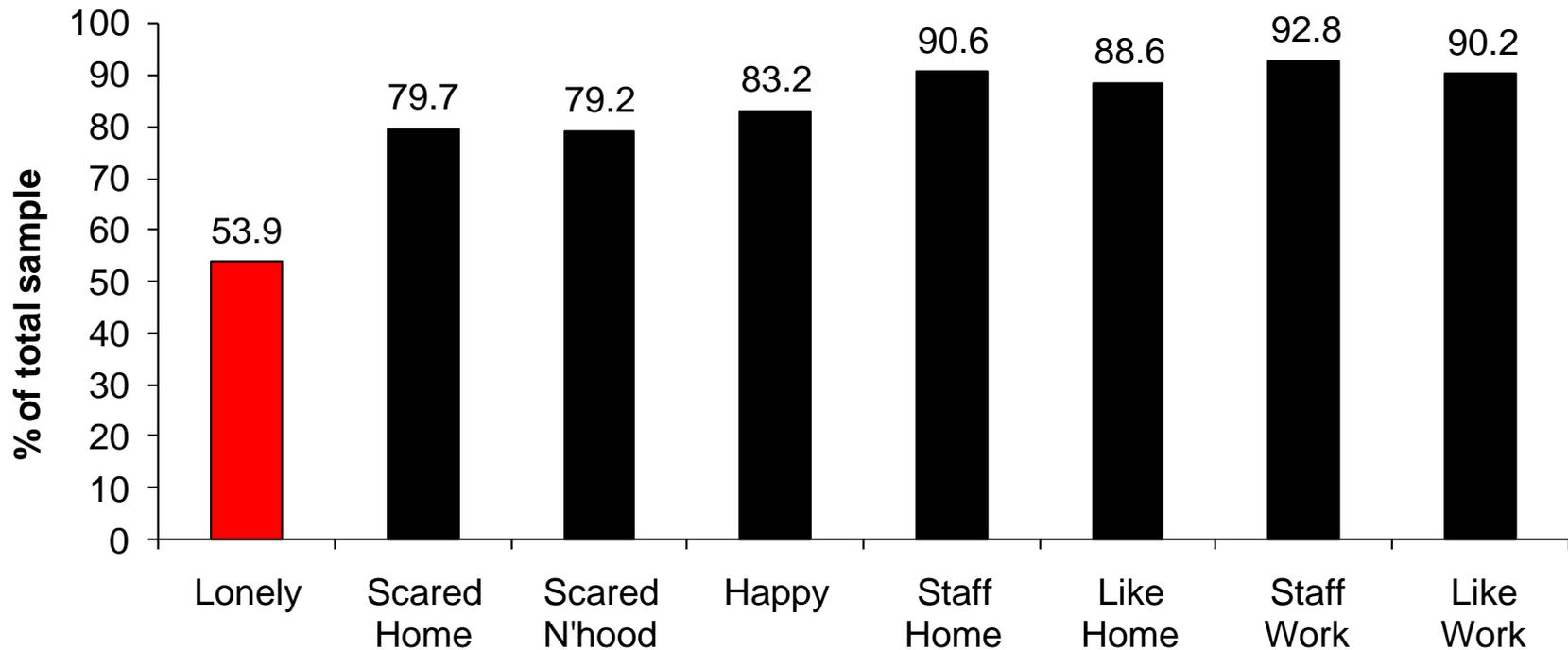
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Of the 49% Receiving Medications...



We've Found That People with ID/DD Are Generally Positive About Their Well-Being in Places of 15 or Fewer Residents; Loneliness is the Most Widespread Problem

Percent with positive well-being outcome



Source: National Core Indicators

Best and Promising Practices

- Person-centered practices Person-centered approaches are designed to assist an individual to plan their life and supports; to increase their personal self-determination, improve their own independence, and support their social inclusion in the community. The provision of supports and services must be designed and delivered through a person-centered lens.
- Positive Behavioral Approaches combined with MH clinical practice
- Employment First Practices
- Individual Resource allocation
- Consumer-direction
- New technology – assistive; communication; monitoring

Part I



Thank You!

National Association of State Directors of Developmental Disabilities
Services

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